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Cover Page Footnote

Illustration by K.M. Spencer

GOVERNMENTAL REGULATION OF MEDICAL DECISION-MAKING:

All In The Name of Baby Doe

by JoAnn Harri

Due to advances in neonatal medical technology, the survival rate for premature and critically ill newborns has increased dramatically over the past quarter of a century. Children who twenty-five years ago would have died well before their first birthday, now often survive. Unfortunately, their survival is often occasioned by severe medical disorders, such as: anencephaly,¹ hydranencephaly,² spina bifida cystica³ complicated by hydrocephalus,⁴ meningomyelocele,⁵ Down's Syndrome⁶ complicated by duodenal atresia,⁷ microcephaly,⁸ and myeloschisis.⁹ In many of these cases, parents and physicians have quietly and privately chosen non-treatment or conservative rather than aggressive forms of treatment and have, through omission, brought about the death of their premature or disabled newborn.

This situation has spawned philosophical, social and ethical implications which extend far beyond the control of either the courts or the government. Nevertheless, the Federal government, in the form of the U.S. Department of Health and Human Services (HHS) has attempted to control this decision-making process by enacting regulations which make it unlawful to discriminate against a handicapped newborn solely on the basis of their handicap. These regulations, commonly referred to as the "Baby Doe Regulations,"¹⁰ were first issued in May 1982, pursuant to § 504 of the Rehabilitation Act of 1973.¹¹ The Baby Doe Regulations were initially promulgated as an interim final rule in March 1983,¹² subsequently invalidated by the DC. Circuit in April 1983,¹³ reissued in July 1983,¹⁴ published as a final rule in January 1984,¹⁵ and again invalidated by the Eastern District¹⁶ and Southern District¹⁷ of New York in February and December 1984, respectively. The government appealed the Southern District opinion in March 1985 and the Supreme Court heard oral arguments on January 15, 1986. A decision is expected by July. The narrow issue to be decided by the Supreme Court is whether § 504 of the Rehabilitation Act of 1973 authorizes governmental control of medical and parental decision-making.¹⁸

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History and Substance of the Regulations

Parents and physicians have long made private treatment decisions regarding their premature or defective newborn,¹⁹ in fact, some commentators have suggested that this practice is merely a continuation of the historical practice of infanticide.²⁰

However, an article published in the New England Journal of Medicine in 1973 made the practice of selective non-treatment of handicapped newborns public, and helped trigger the current legal and ethical debate.²¹ In this article, the authors, two well-respected doctors at Yale New Haven Hospital, revealed the fact that newborns are often allowed to die, or are treated conservatively rather than aggressively, if they are extremely premature or severely disabled. As the authors explained in their introduction:

The experiences described in this communication document some of the grave moral and ethical dilemmas now faced by physicians and families. They indicate some of the problems in a large, special-care nursery where "informed" parents influence the management decisions concerning their infants.²²

This article, along with a highly publicized Bloomington, Indiana case,²³ prompted President Reagan to send a memorandum to the Attorney General and Secretary of HHS on April 30, 1982. The memorandum cited the Bloomington, Indiana case and noted that Federal law prohibits discrimination against the handicapped.²⁴

In response, on May 18, 1982, HHS wrote a letter to approximately 7,000 hospitals putting them on notice that it was "unlawful" (under §504 of the Rehabilitation Act of 1973) for a recipient of Federal financial assistance to withhold from a handicapped infant nutritional sustenance or medical or surgical treatment required to correct a life-threatening condition if: (1) the withholding is based on the fact that the infant is handicapped; and (2) the handicap does not render treatment or nutritional sustenance contraindicated.²⁵ The penalty for noncompliance was the possible loss of Federal funds. In March 1983, ten months later, HHS issued detailed, follow-up, emergency regulations which required the substance of the May 1982 letter to be

displayed conspicuously in every delivery ward, maternity ward, pediatric ward, nursery and intensive care nursery.²⁶ Included in the notice was a toll-free, 24 hour a day "hotline" number that individuals with knowledge of any handicapped infant being discriminatorily denied food or customary medical care were encouraged to call. The regulations provided HHS officials with authority to take "immediate remedial action" to protect the infant (contrary to the normal 10-day waiting period required by 45 CFR 80.8(d)(3)). In addition, hospitals were required to provide access to their premises and medical records to agency investigators, at any time (once again, contrary to the normal business hour rule enunciated in 45 CFR 80.6(c)). These modifications, explained HHS, "were necessary to protect life from imminent harm."²⁷

Responses to the Federal regulations were fairly predictable. Some, but not all, of the favorable responses came from pro-life organizations.²⁸ By contrast, a number of child advocacy groups, although supportive of the basic thrust of the regulations, objected to the method of enforcement,²⁹ and many medical organizations firmly opposed the regulations, finding them both unnecessary and troublesome.³⁰

The interim final rule was scheduled to become effective on March 22, 1983, only fifteen days following its publication. However, on March 18, the American Academy of Pediatrics and others brought suit against HHS and Secretary Margaret Heckler to enjoin enforcement of the rule. U.S. District Court Judge Gesell denied the temporary restraining order, but agreed to hear the case on April 8. Six days later the court held that the interim final rule was invalid because it failed to satisfy the requirements of the Administrative Procedure Act.³¹ The court determined that the rule was a product of "haste and inexperience,"³² and that many relevant factors, including the scope of § 504, were not considered. The court also determined that the Secretary had failed to follow the procedural requirements of 5 U.S.C. § 553(b) and (d).³³ For these reasons, the court determined that the interim final rule was an arbitrary and capricious abuse of agency decision-making in violation of 5 U.S.C. § 706(2)(A).³⁴

The Administration did not appeal the decision, but rather revised the regulations and reissued them in early July as proposed rules.³⁵

The proposed rules were almost identical to the original, with the exception of the following minor changes:

1. The hotline notice need only be posted at "each nurse's station" as compared with "each delivery ward, maternity ward, pediatric ward, nursery and intensive care nursery," as required by the original notice;
2. The minimum size requirement for the notice was reduced to 8.5 by 11 inches;
3. The state child protection agency's phone number was added to the notice;
4. An entirely new section was added mandating that each state's child protective services agency establish pro-

cedures designed to prevent medical neglect of handicapped infants.³⁶

The only substantive modification appeared in the Appendix to the proposed rules, in which HHS listed several examples of decisions that would, in its view, constitute violations of § 504.³⁷ These examples reflect the limited application of the regulations. As one commentator noted:

Because the regulations were written in response to the Bloomington, Indiana case, they fail to reflect the range of congenital anomalies that occur in Neonatal Intensive Care Units and they fail to distinguish between handicaps that call for curative or corrective treatment and handicaps that do not call for treatment because they cannot be cured or corrected.³⁸

HHS received over 16,000 comments to the proposed rules, of which it categorized 97.5% as supportive. However, of the 141 pediatricians who responded, 72% opposed the regulation, as did 77% of the responding hospital officials and health-related organizations.³⁹

HHS responded to the comments on January 12, 1984 by issuing its final rules,⁴⁰ which contain several modifications of the proposed rules. The first modification provides a standard of care requiring "medically beneficial treatment."⁴¹ This change responded to the most obvious deficiency of the original regulations; it provided no guidance at all to physicians regarding their legal obligations, other than to mandate that they follow custom. The final rules do not make clear, however, what constitutes "medically beneficial treatment," other than to say that it must be determined with respect for reasonable medical judgments. Nor do the final rules make clear whether quality of life judgments can be used to determine the existence of a medical benefit.

The second set of changes is merely cosmetic. It reduces the size of the notice to "no smaller than 5 by 7 inches" and changes the location to "where nurses . . . will see it."⁴² This change is an obvious response to the affront many physicians and hospital administrators felt in being forced to post the original notice in a more public place.

The only meaningful addition to the final rules is the advisory model Infant Care Review Committee (ICRC) contained in the Appendix. According to the regulations, ICRCs are designed "to assist hospitals in the development of standards, policies and procedures for providing treatment to handicapped infants and in making decisions concerning medically beneficial treatment in specific cases." However, ICRCs "are not designed to be a substitute for mechanisms to enforce § 504."⁴³ The committees are merely expected to develop treatment guidelines and review specific cases brought to it by those involved in the treatment decision.

The idea for a model ethical review committee did not originate with HHS, quite the contrary. In late April 1985,



the American Academy of Pediatrics (AAP) released their Guidelines for Infant Bioethics Committees, and urged all hospitals to establish such committees.⁴⁴ In fact, the AAP Guidelines were developed in response to the original Baby Doe Regulations, and as an alternative to them. Prior to that, in 1983, the President's Commission for the Study of Ethical Problems in Medicine suggested that in difficult cases, an ethics committee or similar body might be assigned to review the decision-making process in neonatal intensive care units.⁴⁵

There are difficulties inherent in any bureaucratic ethical review committee; however, these difficulties are especially apparent in the HHS model.

Ethical review committees are generally too cumbersome and inept to provide the rapid decision-making necessary to the life and death decisions made in a neonatal nursery. In addition, the existence of ethical review committees necessarily means a reduction of parental autonomy and physician discretion. The HHS model is even more

problematic in that it is heavily weighed in favor of continued treatment. If the family refuses consent, but the ICRC disagrees with the family (whether or not the family is supported in its decision by the physician), the ICRC is expected to recommend to the hospital that a court or child protective agency be notified.

The model is further biased in that HHS perceives the ICRC as its local investigatory arm, noting in the Appendix that its investigators will make immediate contact with the ICRC when a complaint is made to get the ICRC's version of the case, and that HHS "may require a subsequent written version of the ICRC's findings accompanied by pertinent records and documentation."⁴⁶

For these reasons, the HHS model cannot provide hospitals with the impartiality and independence necessary to the maintenance of an effective ethical review committee. Instead, the HHS model would merely serve to extend governmental control of parental and medical decision-making.

Traditional Legal Standards and Their Relationship to the Regulations

The essential problem with the HHS regulations or with any Federal or State law which mandates medical treatment for all handicapped infants is that it obscures the fact that decisions about neonatal medical treatment are fundamentally moral decisions that deal with complex situations which cannot be decided by simplistic Federal mandates.

Traditionally, the law has presumed that parents act with the "best interests of their children"⁴⁷ in mind. However, this deference is not absolute. In particular, where it can be shown that parents have abused or neglected their children or where there is substantial reason to believe that they will do so, the state acting under its *parens patriae* powers can intervene.⁴⁸

Historically, physicians, hospitals and state agencies have gone to court when parents refused medical treatment, even where the treatment conflicts with the parents' religious beliefs,⁴⁹ the child's life is not in imminent threat of danger and neither the child nor the parents believed that treatment was medically indicated.⁵⁰ Courts have intervened and ordered treatment over parental objections in numerous life threatening situations.⁵¹ The state may intervene to insure that a child is given proper medical treatment in life-threatening situations where the custodian of the child has unreasonably refused to allow such treatment.⁵² And in cases where there was no immediate threat to a child's life, some courts have ordered treatment when it is reasonable to assume that the child's physical health will be seriously impaired and cannot be satisfactorily treated at a later time.⁵³

It appears that courts have and will continue to respond to the ethical and moral dilemmas presented by the critically ill newborn in a reasonably flexible and equitable manner. The HHS regulations, however, as one commentator noted:

are difficult to apply to the decisions made in Neonatal Intensive Care Units and virtually impossible to defend in courts of law . . . As high as the stakes are in cases of selective non-treatment, the question is whether federal legal intervention is the best way of handling the problem.⁵⁴

Application and Subsequent Invalidation of the Regulations

Baby Jane Doe was born on October 11, 1983 at St. Charles Hospital in Port Jefferson, New York. She was suffering from multiple birth defects, the most serious of which were spina bifida, microcephaly, and hydrocephalus.⁵⁵ In addition, she exhibited a "weak face," which prevented her from closing her eyes or making a full suck with her tongue, a malformed brain stem, upper extremity spasticity, and

a thumb entirely within her fist. Her physician recommended immediate surgery to reduce the fluid in her skull and close the cystic lesion on her spine. The surgery could increase her life expectancy from a matter of weeks to twenty years, but it would not correct the expected handicapping conditions including severe retardation, (so severe, in fact, that there was an extremely high risk she would never be able to interact with her environment or other people), epilepsy, paralysis, incontinence and constant urinary tract infections.

At the direction of the first pediatric neurosurgeon to examine her, the baby was transferred to State University Hospital at Stony Brook for surgery. However, after lengthy consultations with several physicians, nurses, religious advisors, a social worker, and members of the family, the parents decided to forego the corrective surgery, opting instead for "conservative" medical treatment consisting of good nutrition, the administration of antibiotics, and the dressing of the baby's exposed spinal sac. The physicians agreed with both the reasonableness and appropriateness of this decision. However, on October 16, A. Lawrence Washburn, Jr., a Vermont attorney and right-to-lifer unrelated to the child and the family, acted on a confidential tip and commenced a proceeding in New York State Supreme Court seeking appointment of a guardian *ad litem* for the child and an order directing the hospital to perform the surgery. The trial judge, Melvyn Tanenbaum, who had accepted the Right-to-Life party nomination when he ran for Judgeship in November 1982, appointed attorney William E. Weber as guardian *ad litem* to represent the child, and held a hearing on October 20 to determine whether Baby Jane Doe was "in need of immediate surgical procedure to preserve her life." Weber, who the night before the hearing had told the parents he agreed with their decision, reversed himself at the hearing and argued for immediate treatment on the basis that the medical records disagreed with what the physicians had told him and the parents about the child's prognosis. The court concluded that surgery was necessary and authorized Weber to consent to it. The parents appealed.

One day later the Appellate Division reversed Judge Tanenbaum's decision, ruling that the parents' decision was considered with the best interests of the child in mind, and therefore, there was no basis for judicial intervention. The court found both that the child was not "in imminent danger of death" and that the recommended shunt and spinal closure carried their own risks, including loss "of what little function remains in her legs."⁵⁶

Seven days later, the New York Court of Appeals affirmed the decision of the Appellate Division, relying on different grounds. The Court of Appeals ruled that Judge Tanenbaum had abused his discretion in hearing the case, because Petitioner Washburn had "no disclosed relationship with the child, her parents, her family, or those treating her illness." The court ruled that allegations of child abuse or neglect must be made to the State's Department of Social

Services for appropriate investigation, and since petitioner had failed to do this, dismissed the suit on these procedural grounds.⁵⁷

While the State Court proceedings were still in progress, HHS received a "hotline" complaint from an unidentified private citizen that Baby Jane Doe was being discriminatorily denied medically indicated treatment on the basis of her handicaps. HHS referred the complaint to the New York State Child Protective Services, which on November 7 determined that there was no cause for State intervention. Prior to this, HHS had obtained a copy of the record of the State Court proceedings, which contained the child's medical records through October 19. After personally reviewing the records, Surgeon General Everett Koop concluded that he could not determine the basis for denial of treatment, including whether it was based solely on the child's handicap, without "immediate access to, and careful review of current medical records . . ." Therefore, beginning on October 22, HHS repeatedly requested that University Hospital make available all of Baby Jane Doe's medical records since October 19 so it could conduct a § 504 investigation.⁵⁸ The hospital refused, basing its decision, in part, on the refusal of the parents to release the records and, in part, on "serious concerns both as to the Department's jurisdiction and the procedures it has employed in initiating an inquiry."

The government then brought this action on November 2 to obtain the child's medical records, alleging that University Hospital had violated § 504 and 45 C.F.R. § 80.6(c) by refusing to allow HHS access to information regarding the medical care and hospital services being rendered to the infant.⁵⁹ The parents intervened as defendants, and both the hospital and the parents moved to dismiss the complaint.⁶⁰

The District Court determined that the hospital was not in violation of § 504. The court focused on whether or not it could be "clearly determined" from the record that the hospital was not in violation of § 504. The court concluded that the hospital failed to perform the surgery not because of the child's handicap, but because of parental refusal. The court also found the decision of the parents "reasonable" based on "the medical options available and on a genuine concern for the 'best interests of the child.'"⁶¹

The government appealed, arguing that the hospital has a duty under § 504 to seek judicial review of a parental refusal to consent to surgery.⁶² The parents and hospital argued that § 504 was never intended to serve as a basis for governmental intervention in medical decision-making.⁶³

In responding to these arguments, the Court of Appeals narrowed its focus to one central issue: "Did Congress intend § 504 to reach the conduct HHS seeks to investigate?"⁶⁴ The court determined that § 504 did not give HHS any authority to interfere with treatment decisions involving defective newborn infants. Specifically, the court held that "requiring the hospital either to undertake surgery notwithstanding the parents' decision or alternatively to

petition the state court to override the parents' decision, would impose a particularly onerous affirmative action burden on the hospital."⁶⁵ In this way, the court reasoned, governmental regulation of medical decisionmaking in the case of critically ill infants is an unintended and unwarranted imposition of affirmative treatment obligations which can not be upheld. In reaching this conclusion, the court assumed, without deciding, that § 504 applied to the hospital's neonatal intensive care unit because the hospital received Medicaid and Medicare payments.⁶⁶

The Court of Appeals opinion contains a detailed analysis of the regulatory history, legislative history, statutory language and case-law interpretation of § 504.

The court began its analysis by discussing the regulatory history of HHS and its predecessor the U.S. Department of Health, Education and Welfare (HEW), with respect to § 504. In 1976, HEW adopted the position that § 504 does not give it authority to regulate regarding patients' rights to "receive or refuse treatment." Rather, HEW's authority was simply to make services accessible to the handicapped, so as to provide them with an equal opportunity to receive educational and vocational benefits. In May 1977 HEW explained the nature of the non-discrimination requirement imposed by § 504.

One common misconception about the regulation is that it would require specialized hospitals and other health care providers to treat all handicapped persons. The regulation makes no such requirement.⁶⁷

In fact, it was not until the May, 1983 letter to hospitals that HHS first took the position that § 504 might extend to medical treatment decisions.⁶⁸ "In sum," the court concluded, "the regulatory history of § 504 is inconclusive. HHS's current view of the scope of the statute is flatly at odds with the position originally taken by HEW."⁶⁹

The court then continued its analysis by inquiring into the language, legislative history and congressional intent of § 504.

With respect to the language of § 504, the court determined that in order to find discrimination, three criteria must be met: (1) the existence of a handicap, (2) an otherwise qualified individual, and (3) discrimination based on the handicap. The court observed that it is not entirely clear what "otherwise qualified" means in the context of a medical treatment decision. The court reasoned that the statutory language does not seem to encompass cases like Baby Jane Doe. Although a seriously ill newborn is handicapped, it is only otherwise qualified for treatment because of the existence of the handicap. For there to be discrimination, there must be at least two classes of patients. Here there was only one, those suffering from the handicap.

In contrast, the government argued that there were two classes of patients: those suffering from spina bifida with a reasonable prognosis for intellectual development, and

those like Baby Jane Doe who suffered additional handicaps that made severe retardation possible.⁷⁰

With respect to the legislative history and congressional intent of § 504, the court determined that Congress had "never contemplated that § 504 would apply to treatment decisions of this nature."⁷¹ In fact, the legislative history of § 504 "is devoid of discussion of the treatment of seriously ill newborns." The purpose of § 504 was "to develop and implement through research, training, services and the guarantee of equal opportunity, comprehensive and coordinated programs of vocational rehabilitation and independent living."⁷² Thus, concluded the court, the Act specifically contemplates a goal of equal employment opportunities, rather than standards of medical treatment.

In contrast, the government argued that § 504 was enacted to prevent recipients of Federal aid from basing their decisions regarding the distribution of services and benefits on stereotypes and prejudices concerning the limitations of major life activities faced by the handicapped. Section 504, according to HHS, was enacted to eliminate consideration of the handicap itself from all decision-making, whether it involves access to educational opportunities or distribution of medical benefits.

Finally, the court analyzed the case law interpretation of § 504, beginning with the Supreme Court's opinion in *Southeastern Community College v. Davis*. In *Davis*, the Supreme Court emphasized that "the language and structure of the Rehabilitation Act of 1973 reflects the recognition by Congress of the distinction between the even handed treatment of qualified handicapped persons and affirmative efforts to overcome the disabilities caused by the handicaps."⁷⁴ This decision was later cited by the D.C. Circuit and upheld in 1981.⁷⁵ The requirements imposed on hospitals and physicians by the regulations would be, determined the Court of Appeals, a particularly "onerous affirmative action" unintended by statute.⁷⁶

In response, the government argued that the only affirmative step required of recipient hospitals by the final rules is to post an informational notice . . . The posting of this notice cannot be credibly argued to constitute the kind of excessive regulation prohibited by the *Davis* doctrine.⁷⁷

The court concluded that § 504 does not give authority to interfere with medical treatment decisions involving defective newborn infants. Accordingly, HHS's request to continue its investigation by obtaining access to Baby Jane Doe's medical records was denied.⁷⁸

In March and April 1984, hearings were held in an action brought against HHS by the American Hospital Association challenging the validity of the Baby Doe Regulations.⁷⁹ On plaintiffs' motions for summary judgment, District Court Judge Brient held, without opinion, on the basis of the Court of Appeals' decision in *University Hospital*,⁸⁰ that the regulations were not authorized by the Rehabilitation Act of 1973. The Court held that the regulations are "invalid, unlawful and must be set aside pursuant

to the Administrative Procedure Act, 5 U.S.C. § 706(2)(c), because promulgated without statutory authority."⁸¹

HHS appealed the decision, filing a writ of certiorari on March 24, 1985. The Supreme Court granted the petition in August 1985. The question presented to the court is as follows: "Does § 504 of 1973 Rehabilitation Act prohibit hospital program[s] receiving Federal financial assistance from withholding nourishment or medically indicated treatment from [a] handicapped child, or otherwise discriminating against [a] child, solely because of his handicap?"⁸²

A decision has yet to be reached in this case; however, in light of the foregoing analysis, it will be interesting to see just how far this Administration can go in legislating morality. As one particularly astute commentator observed:

The essential problem with the HHS regulations is that they legislate and mandate the application of a philosophy; their goal is not to prevent discrimination or protect civil rights, but rather to merely enforce a highly controversial and narrowly focused point of view.⁸³

In the context of life and death decisions in the neonatal nursery, such a focus is not only inappropriate but may, in fact, detract from and inhibit the development of programs and support systems necessary to meet the needs of the handicapped. The irony of this situation is most apparent when one realizes the factual situation surrounding the Supreme Court's ruling that § 504 does not require affirmative action.

In *Southeastern Community College v. Davis*,⁸⁴ the Supreme Court considered the claims of a licensed practical nurse that her denial of admission to a college nursing program on the basis of her hearing disability violated § 504. The college had determined that Ms. Davis' impairment was such that, even with a hearing aid, she would be unable to participate fully in the program and function effectively as a nurse. According to Ms. Davis, however, the college should not have taken her handicap into account in determining whether she was "otherwise qualified" for the program, but rather, should have confined its inquiry to her academic and technical qualifications. The Supreme Court disagreed. As it stated, § 504, "by its terms, does not compel educational institutions to disregard the disabilities of handicapped individuals."⁸⁵ Nor does it require affirmative action on the part of the institutions to modify a program to accommodate the specific disabilities of an individual.

It is ironic, indeed, that § 504 has been interpreted by the Administration to prohibit discrimination on behalf of severely handicapped newborns, but has not been interpreted to provide Ms. Davis and other similarly situated individuals, who are only moderately handicapped, with the support necessary to live a full and satisfying life.

Conclusion

It will be interesting to see the effect of the forthcoming Supreme Court decision in *Heckler v. American Hospital Association*⁸⁶ on the opportunities available to the handicapped under § 504.

Will a broad reading of § 504, upholding the Baby Doe Regulations, also imply an even broader reading of § 504's authority; in other words, will Ms. Davis and other similarly situated individuals now be allowed entry into programs such as Southeastern? Or will a broad reading be so narrowly construed to apply only in those cases which will further the Administration's current ethical, moral and philosophical viewpoints?

Conversely, if the lower court's opinion is upheld and the regulations are declared invalid, will Ms. Davis' situation and others like hers become even more difficult? Or will the decision be so narrowly construed as to have no relationship, whatsoever, to the general authority of § 504?

Clearly, there are no simple solutions to the difficult issues presented by the selective non-treatment of seriously handicapped newborns. However, vague governmental mandates are not only inappropriate, but may have ramifications which extend far beyond the boundaries of the neonatal nursery.

FOOTNOTES

1. Anencephaly is a condition of arrested development of the brain; at least the cerebral hemispheres are absent, and sometimes the brain is totally absent.

2. Hydranencephaly is a disorder characterized by the complete or almost complete absence of the cerebral hemispheres.

3. Spina bifida cystica is an abnormality in which the vertebrae have not fully developed.

4. Hydrocephalus is a disorder characterized by rapid enlargement of the head caused by fluid pressure on the brain. When hydrocephalus has appeared at birth and the undeveloped vertebrae are high on the spine, many physicians recommend nontreatment. Lorber, *Early Results of Selective Treatment of Spina Bifida Cystica*, Brit. Med. J., October 27, 1973, at 201.

5. Meningomyelocele is a severe form of spina bifida cystica in which there is a cystic lesion of the spinal column with evidence of neurological dysfunction. This disorder ordinarily results in complete paralysis below the lesion. Left untreated, 98% of spina bifida infants with meningomyelocele die within a year. With adequate medical care, however, spina bifida patients often reach adulthood. MacMillan, *Birth Defective Infants: A Standard, For Non Treatment Decisions*, 30 Stan. L. Rev. 599, 560, n. 4. (1978).

6. Down's Syndrome is a chromosomal abnormality characterized by mental retardation, a thick and protruding tongue, almond-shaped eyes, and a higher than normal susceptibility to infection.

7. Duodenal atresia is an abnormality often associated with Down's Syndrome in which there is a complete absence or obstruction of a portion of the upper part of the small intestine. A minor surgical procedure will alleviate the blockage, however, surveys of pediatricians and pediatric surgeons repeatedly have shown that the majority of doctors polled either would not recommend surgery or would acquiesce in parents' decisions not to operate in such a case. Todres, Krane, Howill & Shannon, *Pediatricians' Attitudes Affecting Decision-Making in Defective Newborns*, 60 Pediatrics 197, 198 (1977).

8. Microcephaly is a disorder characterized by abnormal smallness of the head. Serious mental retardation usually results when the head size is more than two standard deviations below normal size.

9. Myeloschisis is a condition characterized by a cleft spinal cord, caused by the failure of the neural plate to form a complete tube. Newborns with this disorder do not usually survive the first week of life.

10. *Discriminating Against the Handicapped by Withholding Treatment or Nourishment*; Notice of Health Care Providers, 47 Fed. Reg. 26, 027 (1982).

11. Section 504 provides in relevant part: "No otherwise qualified individual . . . shall solely by reason of his handicap, be excluded from the participation in, be denied the benefit of, or be subject to discrimination under any program or activity receiving Federal financial assistance." 29 U.S.C. § 794 (Supp. 1983).

12. *Nondiscrimination on the Basis of Handicap*, 48 Fed. Reg. 9630 (1983) (to be codified at 45 C.F.R. pt. 84) (proposed March 7, 1983).

13. *American Academy of Pediatrics v. Heckler*, 561 F. Supp. 395 (D.D.C. 1983).

14. *Nondiscrimination on the Basis of Handicap Relating to Health Care for Handicapped Infants*, 48 Fed. Reg. 30, 846 (1983) (to be codified at 45 C.F.R. pt. 84) (proposed July 5, 1983).

15. *Nondiscrimination on the Basis of Handicap; Procedures and Guidelines Relating to Health Care for Handicapped Infants*, 49 Fed. Reg. 1622 (1984) (to be codified at 45 C.F.R. pt. 84) (proposed January 12, 1984).

16. *United States v. University Hospital*, 575 F. Supp. 607 (E.D.N.Y. 1983), *aff'd*, 729 F.2d 144 (2d Cir. 1984).

17. *American Hospital Association v. Heckler*, 585 F. Supp. 541 (S.D.N.Y. 1984), *aff'd*, No. 84-6211 (2d Cir. Dec. 27, 1984).

18. *Heckler v. American Hospital Association*, 585 F. Supp. 541 (S.D.N.Y. 1984), *aff'd*, No. 84-6211 (2d Cir. December 27, 1984), *cert. granted*, 54 U.S.L.W. 3053 (U.S. Aug. 6, 1985) (No. 84-1529).

19. Surveys of pediatricians and pediatric surgeons repeatedly have found that the majority of doctors polled either would not recommend surgery for a Down's Syndrome infant with an intestinal blockage or would acquiesce in parents' decisions not to operate in such a case. Todres, Krane, Howill & Shannon, *Pediatricians' Attitudes Affecting Decision-Making in Defective Newborns*, 60 Pediatrics 197, 198 (1977) (51% would not recommend surgery); Shaw, Randolph & Manard, *Ethical Issues in Pediatric Surgery: A National Survey of Pediatricians and Pediatric Surgeons*, 60 Pediatrics 558 (1977) (76.8% of pediatric surgeons and 49.5% of pediatricians would follow parents' wishes to refuse consent for surgery).

20. The contemporary practice of selective nontreatment of handicapped newborns is, in many aspects, a continuation of historical practices of infanticide. The settings and circumstances vary from historical patterns, but infant deaths brought about in neonatal intensive care units often provide parallels to acts of infanticide in early times and places. Although dealing with life-and-death decisions in a sophisticated technological context that earlier generations could not have imagined, current debates about selective nontreatment retrace familiar ground when they focus on the attitudes of parents towards anomalous newborns, the rights and limits of parental discretion, the appropriate roles of physicians in neonatal cases, the proper function of law in cases of infant homicides, and the morality of terminating the lives of some infants with serious congenital anomalies.

R. Weir, *Selective Nontreatment of Handicapped Newborns* 3 (1984).

21. Duff & Campbell, *Moral and Ethical Dilemmas in the Special-Care Nursery*, 289 New Eng. J. Med. 890 (1973).

22. *Id.* at 890.

23. A newborn male, afflicted with Down's Syndrome and a blocked esophagus, was allowed to die with court approval after his parents refused treatment. In regards to the Treatment and Care of Infant Doe, No. GU 8204-004A (Monroe Co. Cir. Ct., April 12, 1982), *writ of mandamus dismissed sub non*, State ex rel. Infant Doe v. Baker, No. 482 § 140 (Ind.

Sup. Ct. May 27, 1982), *cert. denied*, Doe v. Bloomington Hospital, 104 S. Ct. 394 (1983) (case mooted by infant's death).

24. See *supra* note 11.

25. 47 Fed. Reg. 26, 027 (1982).

26. 48 Fed. Reg. 9630 (1983).

27. *Id.* at 9631.

28. J.C. Wilke, a physician and president of the National Right to Life Committee, issued this news release:

Fatal discrimination against Down's Syndrome and other handicapped infants has been increasing for years in this country. This discrimination consists of denial of medical treatment, even food and water, which would be routinely provided to non-handicapped infants. The ethic which promotes infanticide is related to the elitist "quality of life" arguments used to justify abortion-on-demand. Infanticide is a form of barbarism which our nation should emphatically reject."

J.C. Wilke, News Release, May 26, 1982, quoted in Smith, *Handicapped Newborns: Current Issues and Legislation*, Cong. Research Serv. Rep. 2 (July 28, 1982).

29. Holden, *HHS Preparing to Issue New Baby Doe Rules*, 221 Science 1269 (1983).

30. On June 21, 1982, The American Academy of Pediatrics issued its official position regarding the HHS notice:

The effort of the executive branch to solve this complex problem through strict interpretation and enforcement of the letter of § 504 may have the unintended effect of requiring treatment that is not in the best interest of handicapped children. Handicapped persons . . . need health care providers who will carefully examine the appropriateness of specific medical intervention. It will frequently be the case that the use of a specific technology or procedures will not be in the best interest of the handicapped person. Withholding a medical treatment will frequently be both legally and ethically justified in our efforts to do what is right for these patients.

American Academy of Pediatrics: Official Statement, June 21, 1982, quoted in Smith, *Handicapped Newborns: Current Issues and Legislation*, Cong. Research Serv. Rep. 8 (July 28, 1982).

31. 5 U.S.C. § 551 *et seq.* (1982).

32. American Academy of Pediatrics v. Heckler, 561 F. Supp. 395, 400 (D.D.C. 1983).

33. As (HHS's) counsel acknowledged in argument, the regulation is intended, among other things, to change the course of medical decision-making in these cases by eliminating the parents' right to refuse to consent to life-sustaining treatment of their defective newborn. Moreover, the regulation provides for an intrusive on-premises enforcement mechanism that can be triggered by a simple anonymous phone call. Thus it is clearly more than a "clarification or explanation of an existing rule or statute" and affects substantive rights.

American Academy of Pediatrics v. Heckler, 561 F. Supp. at 401.

34. Government intervention into the difficult medical and human decision that must be made in the delivery rooms and newborn intensive care units of our hospitals involves a profound change in the manner in which these decisions affecting the quality of life are made. Any intervention by an agency of the Federal Government should obviously reflect caution and sensitivity, given the present absence of a clear congressional directive.

American Academy of Pediatrics v. Heckler, 561 F. Supp. at 403.

35. 48 Fed. Reg. 30, 846 (1983).

36. *Id.* at 30, 846-30, 852.

37. The Secretary deems the following to be examples — not a comprehensive list — of denials of treatment that constitute a violation of § 504: (1) Down's Syndrome with in-

testinal obstruction, denial of surgery to correct obstruction. Current medical practice is to correct intestinal atresia in infants with no other congenital anomaly . . . Any decision not to correct intestinal atresia in a Down's Syndrome child, unless an additional complication medically warrants such decision, must be deemed a denial of services based on the handicap of Down's Syndrome; (2) Denial of cure or treatment that would be given to a non-handicapped infant, on grounds that a particular infant is potentially blind, or deaf, or paralyzed or lacking limbs; (3) Denial of treatment for medically correctable physical anomalies in children born with Spina Bifida, when such denial is based on anticipated mental impairment, paralysis, or incontinence of such child, rather than on reasonable medical judgments that treatment would be futile or too unlikely of success given complications in the particular case.

48 Fed. Reg. at 30,852 (1983).

38. R. Weir, *Selective Nontreatment of Handicapped Newborns*, 137 (1984).

39. "HHS received 16,739 comments, many of which were based on letter writing campaigns by "right to life" organizations. Annas, *The Baby Doe Regulations: Governmental Intervention in Neonatal Rescue Medicine*, 74 Am J. Pub. Health 619 (1984).

40. 49 Fed. Reg. 1622 (1984).

41. 49 Fed. Reg. at 1652 (1984).

42. 49 Fed. Reg. at 1651 (1984).

43. 49 Fed. Reg. at 1624 (1984).

The advisory model proposed in the Appendix is made up of "seven members including a physician, nurse, hospital administrator, lawyer, lay member, disabled group representative and a member of the hospital staff who will serve as chairperson."

Id. at 1651.

44. American Academy of Pediatrics: Guidelines for Infant Bioethics Committees (1984).

45. President's Commissions for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research: *Deciding to Forego Life-Sustaining Treatment* (1983).

46. 49 Fed. Reg. at 1654 (1984).

47. The prevailing standard, in cases involving parental child concerns, is the "best interests of the child" standard. This standard weighs the welfare and interests of the child above all other considerations.

48. *Haldeman v. Pennhurst State School & Hospital*, 707 F. 2d 703 (3rd Cir. 1983); *Wisconsin v. Yoder*, 406 U.S. 205 (1972); *Pierce v. Society of Sisters*, 268 U.S. 510 (1925); *Meyer v. Nebraska*, 262 U.S. 390 (1923).

49. *Jehovah's Witnesses v. King Co. Hospital*, 278 F. Supp. 488 (W.D. Wash. 1967), *aff'd per curiam*, 390 U.S. 598 (1968); *Muhlenberg Hospital v. Patterson*, 128 N.J. Super. 498, 320 A. 2d 518 (1974); *Matters of Jensen* 54 Or App 1, 633, P. 2d 1302 (1981).

50. *People in Interest of D.L.E.*, 645 P. 2d 271 (Colo. 1982).

51. *Maine Medical Center v. Houle*, No. 74-145 (Super. Ct. Cumberland Co., Me. Feb. 14, 1974). In the Matter of *Storar*, 52 N.Y. 2d 363, 438 N.Y.S. 2d 266, 420 N.E. 2d 64 (1981), *certiorari denied* 454 U.S. 858.

52. *Guardianship of Phillip B.*, 139 Cal. App. 3d 407, 188 Cal Rptr. 781 (1983) (1st Dis. 1983).

53. *Application of Cicero*, 101 Misc. 2d 699, 421 N.Y.S. 2d 965 (N.Y. Sup. Ct. 1979).

54. R. Weir, *Selective Nontreatment of Handicapped Newborns* 137-138 (1984).

55. See *supra* notes 2, 3, and 8.

56. *Weber v. Stony Brook Hospital*, 95 A.D. 2d 587, 467 N.Y.S. 2d 685 (1983).

57. *Weber v. Stony Brook Hospital*, 60 N.Y. 2d 208, 469 N.Y.S. 2d 63, 456 N.E. 2d 1186 (1983).

58. HHS based its authority to conduct an investigation on § 504 of the Rehabilitation Act of 1973. HHS further relied on 45 C.F.R. § 80.6(c),

as incorporated by 45 C.F.R. § 84.61, which states:

(c) *Access to sources of information*

Each recipient (of Federal financial assistance) shall permit access by the responsible Department official . . . during normal business hours to such of its books, records, accounts, and other sources of information, and its facilities as may be pertinent to ascertain compliance with this part . . . Asserted considerations of privacy or confidentiality may not operate to bar the Department from evaluating or seeking to enforce compliance with this part.

Id.

59. *United States v. University Hospital*, 575 F. Supp. 607 (E.D.N.Y. 1983), *aff'd* 729 F. 2d 144 (2d Cir. 1984).

60. The parents and the hospital argued that:

(1) Congress did not intend § 504 to reach decisions regarding health care services provided to infants; (2) Section 504 imposes no affirmative treatment obligations on the hospital beyond providing handicapped persons equal access to its facilities, which the hospital had done; (3) medicare and medicaid reimbursements do not constitute "federal financial assistance," within the meaning of § 504; (4) Baby Jane Doe's medical records were protected by both her and her parents' federal constitutional privacy rights; and (5) the failure of the Federal government to intervene in the state court proceedings barred the instant action under the doctrine of laches.

U.S. v. University Hospital, 729 F. 2d at 148.

61. *U.S. v. University Hospital*, 575 F. Supp. 607, 614-615 (E.D.N.Y. 1983).

62. The government argued that:

(E)xamination of the child's medical record was necessary to determine if she was denied surgery because of her handicap, which would be as unlawfully discriminatory as refusing to perform surgery on an individual because the person was black. Such decisions are not based on medical criteria and are thus not "bona fide medical judgments" . . . the requested records were necessary to determine whether the failure of the hospital to seek a state court order overriding the parents' decision and compelling surgery was itself a violation of § 504's nondiscrimination requirements.

U.S. v. University Hospital, 729 F. 2d at 149.

63. In addition, the parents and hospital argued that "access to the records is barred by New York's physician-patient privilege and the federal constitutional privacy rights of the child and her parents."

U.S. v. University Hospital, 729 F. 2d at 149.

64. *Id.* at 150.

65. *Id.* at 160.

66. Five days after the Court of Appeals reached its decision in *University Hospital*, the Supreme Court decided *Grove City College v. Bell*, 465 U.S. 555 (1984). *Grove City* introduced the concept of program specificity and substantially narrowed the affirmative action requirements imposed upon institutions receiving Federal funds. It is conceivable, in light of *Grove City*, that the "program or activity" in a hospital which receives Federal financial assistance in the form of Medicaid or Medicare payments is the fiscal accounting office, and as a result, only that office and not the intensive care nursery, is obligated to meet the affirmative action requirements of Federal Law.

67. *U.S. v. University Hospital*, 729 F. 2d at 152.

68. *Id.*

69. *Id.* at 154.

70. *Id.* at 150.

71. *Id.* at 157.

72. *Id.* at 158.

73. *Southeastern Community College v. Davis*, 442 U.S. 397, 99 S. Ct. 2361, 60 L. Ed. 2d 980 (1979).

74. *Id.* at 410.

75. *American Public Transit Association v. Lewis*, 655 F. 2d 1272 (DC. Cir. 1981).

76. *U.S. v. University Hospital*, 729 F. 2d at 160.

77. 49 Fed. Reg. 1638 (1984).

78. According to news reports, Baby Jane Doe, whose real name is Keri-Lynn, was discharged from the hospital after undergoing an operation to implant a shunt to allow fluid to drain from her head. Her parents had originally refused to consent to operations to close the opening in her spine. They reportedly decided to give permission for the implant because the fluid build-up was continuing despite the fact that she was otherwise progressing well. Her skin had grown naturally over the opening in her spine. *Washington Post*, Apr. 7, 1984 at A1, col. 4.

79. *American Hosp. Assoc. v. Heckler*, 585 F. Supp. 541 (S.D.N.Y., 1984), *aff'd* No. 84-6211 (2d Cir. Dec. 27, 1984).

80. *U.S. v. University Hospital*, 729 F. 2d 144 (2d Cir. 1984).

81. *American Hospital Association v. Heckler*, 588 F. Supp. 541 at 542.

82. *Heckler v. Amer. Hosp. Assoc.*, 588 F. Supp. 541 (S.D.N.Y. 1984), *aff'd* No. 84-6211 (2d Cir. Dec. 27, 1984), *cert. granted* 54 U.S.L.W. 3053 (U.S. Aug. 6, 1985) (No. 84-1529).

83. Crane, *Section 504 of the Rehabilitation Act of 1973: Is it Authority for Federal Intervention into the Area of Medical Decision-making?* 13 *Capital Univ. L. R.* 645, 658 (1984).

84. *Southeastern Comm. College v. Davis*, 442 U.S. 391.

85. *Id.* at 405.

86. *Heckler v. Amer. Hosp. Assoc.*, 585 F. Supp. 541 (S.D.N.Y. 1984), *aff'd* No. 84-6211 (2d Cir. Dec. 27, 1984), *cert. granted* 54 U.S.L.W. 3053 (U.S. Aug. 6, 1985) (No. 84-1529). Subsequent to the writing of this article, the case was recaptioned *Bowen v. Amer. Hosp. Assoc.*

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